

Gard and Yates v GOSH, the Guardian and the UK: reflections on the legal process and the legal principles

Article (Accepted Version)

Bridgeman, Jo (2017) Gard and Yates v GOSH, the Guardian and the UK: reflections on the legal process and the legal principles. *Medical Law International*, 17 (4). pp. 285-302. ISSN 0968-5332

This version is available from Sussex Research Online: <http://sro.sussex.ac.uk/id/eprint/70266/>

This document is made available in accordance with publisher policies and may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the URL above for details on accessing the published version.

Copyright and reuse:

Sussex Research Online is a digital repository of the research output of the University.

Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable, the material made available in SRO has been checked for eligibility before being made available.

Copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Gard and Yates v GOSH, the Guardian and the UK: Reflections on the legal process and the legal principles

Court Proceedings to Determine a Child's Medical Treatment¹

Questions about Charlie Gard's medical treatment were referred to court by Great Ormond Street Hospital Foundation Trust (GOSH) after his clinicians, who sincerely believed that the burdens of Charlie's daily existence outweighed its benefits, were unable to persuade his parents, Connie Yates and Chris Gard, that experimental therapy was not in Charlie's interests and that active treatment should be withdrawn. The dispute between Charlie's parents and clinicians centred upon disagreement over both the progression of Charlie's condition and the chance of the experimental therapy improving the length and quality of his life. The effect of the court application was to remove decisions about Charlie's future from his parents and place the responsibility for those decisions with the judge. In April 2017, Francis J in the Family Division granted the order sought by the Trust against which Charlie's parents, determined to continue their fight for their son, appealed through the domestic courts and then to the European Court of Human Rights (hereafter ECHR). In July 2017, GOSH referred the case back to the Family Division seeking a view of the judge upon further medical opinions secured by the parents. After further tests, Charlie's parents accepted that Charlie's progressive condition had deteriorated to the point that the proposed treatment could not benefit him. By appealing through the courts his parents were able to delay the outcome but not, as they wished, change it.

¹ Resources relating to the case can be found at: <http://blog.practicaethics.ox.ac.uk/2017/07/the-ethics-of-treatment-for-charlie-gard-resources-for-studentsmedia/> [last accessed 4/8/17].

Disputes between parents and clinicians about the medical treatment that is in the best interests of a seriously ill child are distinctive amongst those brought before judges of the Family Division of the High Court. They are different in significant ways from private law family proceedings brought under the Children Act 1989 where parents are disagreed over their child's upbringing.² The disagreement is not between parents one of whom has sought the assistance of the court.³ And although Counsel for Charlie's parents sought to draw an analogy in terms of the limits placed by the law upon state intervention in family life in care proceedings, these are not public law proceedings under Part IV of the Children Act 1989. Rather, the disagreement is between parents and professionals both of whom have an interest in the child's wellbeing and legal duties to act in the best interests of the child. Legal proceedings are brought at the request of professionals upon whom parents' rely for the provision of medical treatment to sustain the child's life by a public institution, the NHS Trust. As Francis J observed commenting upon the lack of legal aid such cases, 'To most like-minded people, a National Health Service trust is as much an arm of the state as is a local authority'.⁴ The sense that the parental decision is challenged by the state is furthered if, as it invariably does, the court appoints a Guardian to represent the independent interests of the child;⁵

² Procedurally most cases are brought to court by an application by the Trust for the court to exercise its inherent jurisdiction, although in Charlie's case GOSH also applied for a section 8 Specific Issue Order. The differences between these applications are discussed by Jo Bridgeman, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' *Medical Law Review*, (2017) 25, 363-396.

³ The sole exception in the reported case law is the case of *An NHS Trust v SR* [2012] EWHC 3842, [2]. Bodey J noted that treatment could have been provided given the consent of the father but that he understood the decision of the Trust to ask the court given the serious nature of the treatment, chemotherapy and radiotherapy, and the vehement opposition of the mother.

⁴ *Re Gard (A Child)* [2017] EWHC 1909, [17].

⁵ The appointment of a Guardian is 'unusual' in private law proceedings, *BC and EF (In the matter of M and N) (No.2)* [2017] EWFC 49, [13].

a Guardian who may, as did Charlie's Guardian, reach the conclusion, contrary to that of the parents, that the continuation of life-sustaining treatment is no longer in the child's best interests. Further, the issue upon which there is disagreement arises from decisions which the majority of parents will never have to confront in their parenting, of giving life-sustaining medical treatment to or withholding, or withdrawing, life-sustaining treatment from a seriously ill child. These cases are concerned with questions of life or death for the child. Once referred to court, in contrast with other issues of a child's upbringing which may be brought to court for resolution upon which there is little expert evidence, determination of the child's best interests is inevitably focused upon the medical evidence. Evidence which clinicians are better placed than the child's parents to secure and to understand. The significant differences from other family proceedings raise questions as to whether distinct processes and principles are required for the conduct of such cases.

Writing back in the 1980s, when the body of medical law was very limited, Ian Kennedy argued that whilst areas of medical practice that raise social, political and moral questions should not be left to the individual practitioner⁶ neither are they best regulated by case law. Developing the law through 'hastily convened hearings', he argued, amounted to an 'interstitial form of law-making'.⁷ Yet, the law has been left to develop on a case by case basis over the past forty years. This one case, raising numerous ethical and legal issues, highlights the need for a thorough review of children's healthcare law to develop legal principles and processes specific to the particular needs of children,

⁶ Ian Kennedy, 'What is a Medical Decision?' in *Treat Me Rights: Essays in Medical Law and Ethics*, (Oxford, Oxford University Press, 1988), 19-31.

⁷ Ian Kennedy, *The Unmasking of Medicine*, (London: George Allen & Unwin, 1981, revised 1983), 126.

parents and professionals in these cases.⁸ It is notable, for example, that when in 2006 the Nuffield Council on Bioethics reviewed critical care decisions in fetal and neonatal medicine,⁹ the Council did not offer a single solution but a number of proposals to support decision making in these complex cases including the development of the definition of ‘born alive’,¹⁰ guidelines on the institution of intensive care for babies born under 26 weeks gestation,¹¹ a Code of Practice detailing legal obligations upon practitioners with respect to late termination of pregnancy,¹² standards for the provision of information,¹³ and the clarification of the criteria for good practice in judging best interests.¹⁴ To argue the case for a comprehensive review of children’s healthcare law, this commentary examines the Charlie Gard case as it progressed through the courts.

The facts

Born in August 2016, Charlie appeared to be an entirely healthy baby. At the age of eight weeks, Charlie started to have difficulty feeding and was admitted to hospital with aspiration pneumonia where he remained on a ventilator and fed by naso-gastric tube for the rest of his short life. He was diagnosed with an extremely rare, inherited, progressive, condition, mitochondrial depletion syndrome, RRM2B. Mitochondrial

⁸ Some of the ethical issues have been explored in articles by Dominic Wilkinson and Julian Savulescu published in *The Lancet*, *Journal of Medical Ethics* and *British Medical Journal* as well as a number of blogs by both authors, links to which can be found at: <http://blog.practicaethics.ox.ac.uk/2017/07/the-ethics-of-treatment-for-charlie-gard-resources-for-studentsmedia/> [last accessed 4/8/17].

⁹ Nuffield Council on Bioethics, *Critical care decisions in fetal and neonatal medicine: ethical issues*, 2006.

¹⁰ *Ibid.*, 9.11.

¹¹ *Ibid.*, 9.11-9.19.

¹² *Ibid.*, 9.10.

¹³ *Ibid.*, 9.51-9.54.

¹⁴ *Ibid.*, 9.26-9.34.

conditions affect the generation of the energy supply of cells,¹⁵ in Charlie's case affecting his ability to move, breathe, neurological functioning, and hearing.

Following what was described by one of the GOSH consultants as a 'parent-driven exploration of all alternatives internationally', his parents wanted Charlie to try nucleoside bypass therapy. Although the therapy was experimental, it had never been administered to a child with the form of mitochondrial depletion syndrome which Charlie had,¹⁶ and although there was no prospect of a cure his parents thought it offered him a chance of improving the length and quality of his life (FD(April), [107-112]). Charlie's parents were in contact with parents of children who had received nucleoside therapy for a similar mitochondrial condition, TK2, and whose quality of life had improved. Charlie's parents were thus determined that he should have this 'one shot, one chance of life'. His clinical team considered this request and prepared an application to the Rapid Response Clinical Ethics Committee to request approval to attempt the therapy. However, before they could do so, in January 2017, the frequency of Charlie's seizures increased which his clinicians believed caused him severe and irreversible brain damage. As a consequence, his clinicians concluded that the burdens of everyday living outweighed the benefits and that it was not in his interests to be maintained on a ventilator for the administration of treatment which was of uncertain benefit. Second opinions from 'world leading authorities' supported their conclusion that withdrawal of life-sustaining treatment was reasonable and in accordance with

¹⁵ Department of Health, *Mitochondrial Donation: A consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child*, 2014, 1.4.

¹⁶ Francis J observed that the therapy was also referred to as pioneering. However, the judge pointed out that the therapy had not been tried in humans or tested on mice with the condition that Charlie has so it must be considered experimental rather than pioneering, *GOSH v Yates & Gard* [2017] EWHC 972, [49].

RCPCH guidelines.¹⁷ Professor A, an expert in mitochondrial conditions at GOSH, was concerned that Charlie had a conscious experience of pain but was unable to express it. The intensive care he was receiving including ventilation and regular suctioning of his airways are known to cause pain and suffering.¹⁸ His devoted parents, who spent hours with him every day, did not accept his doctors' assessment of the severity of his brain damage. They believed that he had periods of wakefulness, opened his eyes, knew who his parents were, responded positively to them and gained comfort from them.¹⁹ Commencing the lengthy legal battle, GOSH applied to court for a declaration under its inherent jurisdiction and a Specific Issue Order under s.8 of the Children Act 1989 that it was not in Charlie's best interests to be given nucleoside therapy and that it was lawful to withdraw ventilation and provide palliative care. The issue before the court was novel to the extent that it addressed both the question whether it was lawful and in Charlie's best interests to receive experimental therapy and whether it was in his best interests for life-sustaining treatment to be withdrawn. The court order sought by GOSH was unprecedented in that it not only addressed the legality of the care plan the GOSH clinicians wished to implement, despite the lack of parental agreement, but also the legality of the provision of therapy by a doctor in the US who was, at that time, offering to administer it.

¹⁷ *Ibid.*, [60]. RCPCH framework for good medical practice, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*, 2015, (2015) Archives of Diseases in Childhood 1-23, doi: 10.1136/archdischild-2014-306666 [last accessed 04/08/17].

¹⁸ *Ibid.*, [113-114].

¹⁹ *Ibid.*, [107-112].

Decisions about a child's medical treatment are made by parents, in the exercise of their parental responsibility,²⁰ which requires them to make decisions as to the treatment, from the options available, they consider to be in the best interests of the child.²¹ But the child is the patient to whom doctors have legal duties including to treat according to their professional judgment of the best interests of the child. As Hedley J explained in one of his judgments concerning the future medical treatment of Charlotte Wyatt, a child with a complicated medical condition as a result of prematurity, doctors will seek to accommodate parental wishes as far as 'professional judgment and conscience' allow.²² Approaching decisions about the medical treatment that is in the best interests of a seriously ill child from different perspectives, with different knowledge and experiences,²³ doctors and parents may reach different conclusions as to what is best for a child. Where clinicians are of the opinion that provision of the treatment the child's parents request would be contrary to their professional conscience, fulfilment of parental duty conflicts with fulfilment of professional duty. Where alternative means to resolve the disagreement have been exhausted, the Trust is under a duty to refer the matter to court.²⁴ Although there is no clear guidance on the steps or measures the law requires clinicians or Trusts to take prior to referral to court. Once court proceedings have commenced, parents who were the decision-makers by virtue of parental responsibility then depend upon the legal advice provided by solicitors, the barristers instructed to present their case, and upon the values and principles of the judge upon

²⁰ Children Act 1989, s 3(1). *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] Fam 147, 178.

²¹ *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] Fam 147, 179.

²² *Portsmouth NHS Trust v Wyatt* [2005] EWHC 2293, [41].

²³ Margaret Brazier, 'An Intractable Dispute: When Parents and Professionals Disagree' *Medical Law Review*, (2005) 13, 412-418.

²⁴ *Glass v United Kingdom* (2004) 39 EHRR 15, [79].

whom the law confers decision-making responsibility. As Francis J rhetorically posed in his April judgment, ‘Some people may ask why the court has any function in this process, why can the parents not just make the decision for themselves?’: ‘The answer is that, although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child’s best interests. The Great Ormond Street Hospital has made an application and it is my duty to rule on it, given that the parents and the hospital cannot agree on the best way forward.’²⁵

High Court Proceedings²⁶

At the pre-trial hearing in March 2017, an independent Guardian was appointed to represent Charlie and Francis J gave his parents a month to obtain evidence about the proposed experimental therapy.²⁷ During which time, his parents through crowdfunding, raised in excess of £1.3m to pay for Charlie’s treatment in the US.²⁸ Although, as Francis J stated in his judgment, it was not a question of funding but whether it was in Charlie’s best interests for him to undergo a trial of the therapy and to remain on intensive care support whilst it was tried.²⁹ GOSH had previously

²⁵ *Supra* n.16, [11].

²⁶ *GOSH v Yates & Gard* [2017] EWHC 972, delivered on 11 April 2017, published on 3 May 2017.

²⁷ *Ibid.*, [31].

²⁸ *Ibid.*, [81]. <https://www.gofundme.com/please-help-to-save-charlies-life> [last accessed 4/8/17]. Prior to administration, USA Food and Drug Administration authority would be required for first ever use in a human being of 4 NBT compound.

²⁹ *Ibid.*, [81].

administered nucleoside therapy to children with other mitochondrial conditions.³⁰ Had Charlie's clinicians, and then the judge, agreed that the trial of therapy was in his best interests, subject to ethical approval, it would have been provided.

Judges are regularly asked to determine the fate of children whose doctors have concluded, but whose parents do not agree, that further treatment offers limited benefits in terms of quality or quantity of life. In the months during which Charlie's care was before the courts, there were three cases decided and published on Bailii in which the High Court declared that it would be lawful to withhold life-sustaining treatment from a child.³¹ Reported judgments suggest that there are examples of parents who, having listened to the evidence presented in the court proceedings, are better able to understand the clinicians' reasoning and reconcile themselves to the clinical view of what is best for their child.³² Some parents may accept the ruling of the court as an authoritative determination with which they must comply, as a final decision meaning they have done all they can for their child. Not all cases take the form of disputes, for example, where a child is in local authority care, questions about ending active treatment must be referred to court for determination even if all with parental responsibility are agreed

³⁰ GOSH's position statement of the 13th July, [13], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 4/8/17].

³¹ *A Local Authority and An NHS Trust v MC & FC & C* [2017] EWHC 370 (lawful to withhold invasive treatment and redirect care from life-sustaining treatment to palliative care); *GOSH v NO & KK & MK* [2017] EWHC 241 (lawful to withhold invasive and aggressive treatment); *An NHS Hospital Trust v GM, DK and HK* [2017] EWHC 1710 (lawful to withhold further neurosurgical intervention and, in the event of a cardiac arrest, cardiac resuscitation). The judgment in *An NHS Trust v BK, LK & SK* [2016] EWHC 2860 (lawful to move to palliative care) was published in April 2017 although it had been decided in November 2016. The delay to publication was to avoid having to ask the child's parents about publication immediately following the death of their son.

³² *Re RB* [2009] EWHC 3269; *A Local Health Board v Y* [2016] EWHC 206.

that this is best for the child.³³ Yet, there are plenty of examples from the reported cases of parents who have not been convinced that the independent, objective, decision of the judge or as Charlie's mother, Connie Yates, put it a stranger,³⁴ better reflects the interests of their child than their own assessment. For example, despite unsuccessfully challenging the refusal of Cambridge District Health Authority to fund an extra-contractual referral for further treatment for acute myeloid leukaemia, Jaymee Bowen received the treatment in the private sector, funded by an anonymous benefactor.³⁵ The parents of baby C applied for permission to appeal against the order of the court authorising a blood test to determine C's HIV status. By the time the Court of Appeal considered their application, three days before the test was due to be performed, the parents and child could not be located and were believed to have left the jurisdiction in order to avoid the test.³⁶ C's mother was quoted in the press expressing the view that parents should make decisions on behalf of their child and speak for them until the child is old enough to make her own decisions and objecting to state intervention into family life.³⁷ In such a situation, court proceedings become merely an adversarial, stressful, increasingly high-profile, stage in the ongoing disagreement between two sides, parents and professionals, who are genuinely concerned to do what is best for the child. Proceedings which cannot be said successfully to resolve the issue. In cases where trust

³³ *K (a minor)* [2006] EWHC 1007; *Kirklees Council v RE and Others* [2014] EWHC 3182.

³⁴ Alison Smith-Squire, 'We STILL won't let Charlie go – and I defy any parent to say we are wrong', MailOnline, 14 April 2017, <http://www.dailymail.co.uk/news/article-4413182/Charlie-Yates-mother-gives-heart-breaking-interview.html> [last accessed 4/8/17].

³⁵ *R v Cambridge District Health Authority, ex parte B* [1995] 1 FLR 1055.

³⁶ *Re C (HIV Test)* [1999] 2 FLR 1004.

³⁷ Angela Levin, 'HIV-test couple flee abroad with daughter', Daily Mail, 18/9/99, 19.

has broken down, in which the ‘partnership’ of care³⁸ has unravelled and parents and clinicians have strongly held opposing views about what is best for a child, the question must be whether decisions about a child’s medical treatment are really best made by judges following the presentation of the evidence of the opposing sides. Although particularistic, focused upon judicial determination of the best interests of the specific child, court proceedings feel adversarial; parents fighting the professionals upon whom they depend, and where the court appointed Guardian agrees with the clinical assessment, the state, for their child’s life.

The applicable legal principles by which a judge of the Family Division decides applications from Trusts to authorise the withholding or withdrawal of life-sustaining treatment from a child were developed in the early decisions of the Court of Appeal in the late 1980’s and early 1990’s. In the cases of *Re C*,³⁹ *Re J (1990)*,⁴⁰ and *Re J (1992)*,⁴¹ the Official Solicitor (the former version of the Guardian in Charlie’s case) sought guidance from the court, in the absence of legislative guidance, for those with responsibility for the child. The legal principles can now authoritatively be found in the ‘intellectual milestones’ noted by the Court of Appeal judgment in *Wyatt*,⁴² set out as ten propositions by Holman J in *Re MB*.⁴³ Where the matter is brought to court, the

³⁸ RCPCH, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*, 2015, (2015) Archives of Diseases in Childhood 1-23, 2.4.1, doi: 10.1136/archdischild-2014-306666 [last accessed 28/4/17].

³⁹ *Re C (a minor) (wardship: medical treatment)* [1989] 3 WLR 240, April 1989.

⁴⁰ *Re J (a minor) (wardship: medical treatment)* [1991] 2 WLR 140, October 1990.

⁴¹ *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507, June 1992.

⁴² *Wyatt & Another v Portsmouth Hospital NHS & Another* [2005] EWCA Civ 1181, [87], approving Hedley J in the court below *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247.

⁴³ *An NHS Trust v MB* [2006] EWHC 507, [16].

court must decide it and the duty of the judge is to determine the course of action that is in the best interests of the child. Best interests must be assessed in the widest possible sense, not just medical but also ‘emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations’,⁴⁴ arrived at through a balance sheet of benefits and burdens. Beyond best interests, the judge is directed to consider the child’s quality of life, from the perspective of the child, and to recognise the strong, but not irrebuttable, presumption in favour of the prolongation of life. The judge makes an independent assessment of the child’s best interests, yet legal proceedings appear to be a contest between the claims of adults to know what is best for the child in which the parental decision is challenged by the Trust whose doctors cannot be required to treat contrary to their professional judgement.

During the three day hearing in April 2017, Francis J heard evidence from Charlie’s clinicians and nurses, experts from the UK, the US doctor who was prepared to trial the therapy and Charlie’s parents. Focused upon their child, parents may become experts in their child’s condition and its treatment; they will be the experts in their child’s experience of their condition, its treatment, their pleasures, and pain. Francis J, as is common in such cases, acknowledged that the parental evidence may be of particular value because parents have particular knowledge of their child but, at the same time, the court will be ‘mindful’ that their views may be ‘coloured by their own emotion or sentiment.’⁴⁵ During the hearing Charlie’s parents had to listen to accounts of his lack of capacities with which they fundamentally disagreed and to assessments of his deterioration which they did not recognise. Charlie’s parents believed that he was

⁴⁴ *An NHS Trust v A* [2007] EWHC 1696, [40].

⁴⁵ *Supra* n. 43, [16(x)].

stable and that his condition had not deteriorated since the time when the clinicians had been prepared to trial the therapy. Parents in such cases may be able to get evidence of ‘research and experimentation’, of ‘ideas and possibilities’ or reports of ‘success stories’.⁴⁶ However, it may be difficult for them to secure evidence of properly conducted research studies of the treatment they wish their child to have which Bodey J stated in the earlier case of *SR*, would be required if a court is to be convinced that it was in the child’s best interests to receive it.⁴⁷ The US doctor who was prepared to try the therapy gave evidence, via a video link, to the effect that there was a theoretical chance of a ‘modest difference to life expectancy’, and a ‘low, but not zero’ probability of the treatment being of benefit to Charlie’s brain although it ‘almost certainly’ could not reverse structural brain damage.⁴⁸ In his evidence he betrayed his lack of specific knowledge of the extent to which Charlie’s condition had affected him. On the issue of the withdrawal of ventilation he said, ‘perhaps if I were there, I would support it. Not seeing the child, not seeing the progression, it is difficult for me to make an assessment.’⁴⁹ In the July proceedings, Francis J explained that the court could not rely upon the evidence of a doctor who had not examined the child.⁵⁰ Perhaps this was a ‘remarkably simple proposition’ but it was not one that was clear to Charlie’s parents or lawyers in their presentation of the evidence for the first hearing. Had this been made clear to them during the April hearing, it may also have come to light at that point that neither had the US doctor examined Charlie’s medical records, tests results or the

⁴⁶ Charlie’s parents were supported by those whose children had received the therapy for other mitochondrial syndromes, Lucy Johnston, ‘Charlie Gard: support from family whose son survived following pioneering treatment’, *The Express*, 18/6/17, <http://www.express.co.uk/news/uk/818272/charlie-gard-support-family-son-survived-pioneering-treatment> [last accessed 4/8/19].

⁴⁷ *An NHS Trust v SR* [2012] EWHC 3842, [25].

⁴⁸ *Supra* n.16 [101-106]).

⁴⁹ *Ibid.*, [99].

⁵⁰ *Supra* n.4, [12].

second opinions. Whilst there was an open invitation from GOSH to the US doctor, it was only at the invitation of the judge in July that the doctor, by then named as Professor Hirano, came to London to examine Charlie, his test results and his records. All the time that Professor Hirano was offering Charlie a trial of the therapy, Charlie's parents retained their hope that there was a chance of a longer, and better quality of, life for their son.⁵¹ To ensure that the judge has the evidence necessary to undertake the thorough assessment of the best interests of the child that the law requires, consideration needs to be given to assisting parents to secure what reliable evidence there is of the course of action they believe is best for their child.

The evidence available to Francis J in April from the UK doctors, shared by those from whom they had secured second opinions, was that 'the prospect of the nucleoside treatment having any further benefit is as close to zero as makes no difference. In other words, ... it is futile',⁵² meaning 'pointless and of no effective benefit'.⁵³ This medical evidence together with the view that Charlie, hospitalised, ventilated, tube-fed, did not have a 'quality of life ... that should be sustained without hope of improvement',⁵⁴ led to the conclusion that neither the therapy nor continued ventilation was in Charlie's best interests. Counsel for Charlie's parents pointed to the novel issues raised for the law in

⁵¹ *Supra* n.16 [111].

⁵² *Ibid.*, [119].

⁵³ *Ibid.*, [90].

⁵⁴ *Ibid.*, [126]. Francis J described this as a consensus view. However, agreement that the status quo should not be continued was premised upon very different views as to the implications of this conclusion. His clinicians considered that it followed that life-sustaining treatment should be withdrawn, whilst for his parents it meant that he should be given the therapy which they believed presented the chance of improving his quality of life. Chris Gard's evidence is noted in GOSH's position statement of the 13th July, [5], <https://www.serjeantsinn.com/news/charlie-gard-osition-statements/> [last accessed 4/8/17].

that there were no previous ‘cases where life sustaining treatment has been withdrawn, even from a profoundly disabled child with a desperately poor quality of life, where there is an available treatment which has the potential materially to improve that quality of life’.⁵⁵ On the basis of his findings of fact, Francis J responded to the effect that he considered it was ‘putting it far too high to say that there is an available treatment with potential materially to improve Charlie’s quality of life’.⁵⁶ Having reached conclusions on the evidence, Francis J made the declaration sought by the Trust that it was ‘lawful, and in Charlie’s best interests, not to undergo nucleoside therapy’.⁵⁷ Further that it was lawful to withdraw ventilation and provide palliative care, despite his parents’ objections.⁵⁸ Holding on to the hope offered by Professor Hirano and firm in their view that Charlie’s condition had not deteriorated as much as his doctors considered, the judgment of Francis J did not change his parents’ minds.

Court of Appeal⁵⁹

Parents of seriously ill children will use all means available to secure the best possible treatments for their child.⁶⁰ For Charlie’s parents, this meant continuing their fight through the courts in the hope that their opinion of Charlie’s current condition and their belief that the therapy offered a chance of improving his quality of life, to which Charlie was entitled, would prevail. Yet, these were matters of fact, upon which Francis J had

⁵⁵ *Ibid.*, [124].

⁵⁶ *Ibid.*, [124].

⁵⁷ *Ibid.*, [27].

⁵⁸ *Ibid.*, [27].

⁵⁹ *In the Matter of Charles Gard* [2017] EWCA Civ 410.

⁶⁰ Jo Bridgeman, ‘‘Leaving No Stone Unturned’’: contesting the medical care of a seriously ill child’ (2017) 29 CFLQ 63. This does not mean disagreement, disputes or legal proceedings are inevitable. To the contrary, the vast majority of parents will be able to agree with their child’s doctor upon a course of treatment that is best for their child, including when treatment options have been exhausted or active treatment should be withheld or withdrawn.

found on the evidence before the court, and were not appealable. First, permission to appeal has to be given by either the judge at the original Family Division hearing or by the Court of Appeal. Permission will only be given if there is a prospect of the appeal succeeding or if there is a compelling reason for the appeal to be heard.⁶¹ An appeal can only be brought on the grounds that the decision of the lower court was wrong or unjust because of a serious procedural, or other, irregularity in the proceedings in the lower court.⁶² As a consequence, in comparison with the High Court hearing which focused upon the different view of the facts held by Charlie's parents and clinicians, the appeal courts were concerned with legal argument. Francis J refused, but the Court of Appeal granted, permission to appeal on the issue of whether a different approach should be adopted where there is a choice between two viable treatment options to that adopted when there is no alternative treatment and upon the question of the jurisdiction of the court where both holders of parental responsibility are agreed that an alternative treatment is in their child's best interests.⁶³ The Court of Appeal hearing took place six weeks after the High Court hearing, the complex argument crafted by a new legal team and represented by new Counsel, Richard Gordon QC, slotted into one day found in the Court's busy schedule. Notably, in legal terms Charlie's parents appeal was opposed not only by the hospital but also the Guardian, as independent representative of Charlie's interests, who having visited Charlie in hospital, spoken to his parents, doctors and nurses, and listened to the oral evidence at the hearing, had reached the same conclusion as to Charlie's best interests as the judge.⁶⁴ This served further to distance the parties as Charlie's parents believed they were the ones most closely concerned

⁶¹ Civil Procedure Rules, 52.6(1).

⁶² Civil Procedure Rules, 52.21(3).

⁶³ *Supra* n.59, [36].

⁶⁴ *Supra* n.16, [116-122].

with, and best placed to represent, Charlie's interests. Whilst as both the Supreme Court and European Court of Human Rights stressed, it is important that the child is independently represented, it is understandable that Charlie's parents felt that the Guardian was supporting the position of the Trust leaving them to defend their child's right to life. Whilst the position adopted by the Guardian was reached following a careful review of the evidence, this does raise issues for consideration of the representation of the child separately from his or her parents and from his or her clinicians.

Given the simplicity and clarity of the law and the discretion it gives to a judge in assessing the best interests of the child, it was necessary for Counsel for Charlie's parents to try to distinguish Charlie's situation from all the others in which a court has been asked to authorise the withholding or withdrawal of life-sustaining treatment from a child and, from there, to argue that the law as applied to Charlie's situation should be different. The submission, which was rejected by the Court of Appeal, was that where there is a doctor who, in his or her professional opinion, is prepared to administer a viable alternative treatment, parental preference should only be overridden if it is likely to cause the child 'significant harm'.⁶⁵ McFarlane LJ stated that there was no 'factor or filter' before the court evaluates the best interests of the child.⁶⁶ Furthermore, that as the judge had found that administration of nucleoside therapy would be futile, be of no benefit and merely prolong Charlie's 'awful existence', there was no viable alternative before the court.⁶⁷ Finally, although it had not been addressed in the court below, McFarlane LJ concluded that had Francis J been invited to find whether Charlie was

⁶⁵ *Supra* n.59, [58].

⁶⁶ *Ibid.*, [94].

⁶⁷ *Ibid.*, [97].

currently suffering significant harm he would have so concluded⁶⁸ and, it followed, significant harm would result from the continuation of ventilation and Charlie's life in order to administer nucleoside therapy.⁶⁹ Thus, the court found that the submissions could not be supported as a matter of fact rendering irrelevant the question of a distinction in law. Although it is notable that there was no analysis of significant harm in the context of the medical treatment of a child generally or specifically of a seriously, a terminally, ill child requiring mechanical ventilation to sustain life and whose parents wished him to receive experimental therapy.

The second ground of appeal was that the application by GOSH to prevent another providing the treatment was beyond the powers of the hospital as a public authority and in the absence of significant harm outside the court's jurisdiction.⁷⁰ The Court of Appeal preferred the submission of Ms Gollop QC for the hospital that the issue had arisen between the parents and the clinicians which the Trust had properly brought before the court for a judge to decide according to the best interests of the child.⁷¹

Parental hopes were thus raised by the hearing of their appeal. But, as Charlie's parents found, appeal against the decision of the first instance judge is usually unsuccessful. Only in the case of *Re T* in 1997 was the parental appeal successful on a point of law and the decision of the court at first instance as to the best interests of the child overturned.⁷² In **all** other cases concerned with the medical treatment of a young and dependent child, whilst the terms of the declarations made by the High Court judge may

⁶⁸ *Ibid.*, [114].

⁶⁹ *Ibid.*, [115].

⁷⁰ *Ibid.*, [84].

⁷¹ *Ibid.*, [88].

⁷² *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

be amended, the effect of declarations made upon application of the Trust authorising doctors to proceed, against parental wishes, has been upheld.⁷³ Whilst the legal argument was necessarily constructed in the attempt to reverse the decision of the judge at first instance, Counsel for Charlie's parents made an important point about distinctions between cases of children's medical treatment, which the Court of Appeal, concerned not to disrupt forty years of case law, was not prepared to entertain. Cases, it should be emphasised, which were each concerned with the assessment of the best interests of a seriously ill child and not more general, but crucially important, questions about the balance between parents, professionals and the state in the protection of the welfare, interests or rights of the child. To continue their fight for Charlie, his parents needed permission to appeal to the Supreme Court.

Permission to appeal to the Supreme Court Refused⁷⁴

No case concerning the medical treatment of a young and dependent child has been considered by the Supreme Court, or its predecessor the House of Lords. In the 1980s, the House of Lords decided *Gillick*,⁷⁵ which concerned the hypothetical legal question of the legality of contraception and hence medical treatment to a child under the age of 16, and *Re B*⁷⁶ which concerned the non-therapeutic sterilisation of a minor with learning difficulties. The Supreme Court in *Yates* denied the parents' permission to appeal. Lady Hale, giving the reasons for the Justices' conclusion after a short

⁷³ High profile examples include the conjoined twins case *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480 and the treatment of Charlotte Wyatt, *Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWCA Civ 1181.

⁷⁴ *In the matter of Charlie Gard (Permission to Appeal Hearing)*, 8 June 2017, <https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html> [last accessed 4/8/17].

⁷⁵ *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.

⁷⁶ *Re B (A Minor) (Wardship: Sterilisation)* [1987] 2 WLR 1213.

retirement following two hours of argument, explained that the hospital was entitled to ask a judge to decide about Charlie's future medical treatment and the judge was entitled to do so. Further, that the judge had made findings of fact that could not be challenged on appeal and had applied the correct test to those facts to reach the conclusion he had. The findings of fact which the parents continued to dispute were not open to questioning and the case did not raise an arguable point of law of general importance. Thus, the Supreme Court declined to review the applicable legal principles, developed on a case by case basis by the lower courts, and upheld the order made by Francis J some eight weeks earlier. Charlie needed a final decision on his future treatment and the Supreme Court wished to give it yet were obliged to agree a further stay to the order given the parents' application to the ECHR.

Application to European Court of Human Rights deemed inadmissible⁷⁷

Domestic case law on children's medical treatment has adopted the position that whilst ECHR rights are engaged they confirm rather than 'alter or add to established principles of English domestic law' so that 'specific consideration' of the ECHR is not necessary.⁷⁸ The view that English Law is compatible with Convention Rights in such cases was confirmed by the ECHR in *Glass v UK*.⁷⁹ In *Glass*, the ECHR determined that doctors had breached David Glass's Article 8 right to private and family life when morphine was administered to him, against the refusal of consent from his mother.

⁷⁷ *Charles Gard and Others v United Kingdom*. Application no. 39793/it 17, 28 June 2017, [http://hudoc.echr.coe.int/eng#{\"documentcollectionid2\":\[\"DECGRANDCHAMBER\",\"ADMISSIBILITY\",\"ADMISSIBILITYCOM\"\],\"itemid\":\[\"001-175359\"\]}](http://hudoc.echr.coe.int/eng#{\) [last accessed 3/7/17].

⁷⁸ *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147, Robert Walker LJ, 257; *An NHS Trust v A* [2007] EWHC 1696, [44]; *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 [25].

⁷⁹ *Glass v United Kingdom* (2004) 39 EHRR 15.

Whilst the court concluded that English law complied with the Convention, failure to comply with that law had resulted in an interference with David's Article 8 right and, although his doctors had acted with a legitimate aim (in accordance with their clinical judgment of David's best interests), administration of diamorphine against his mother's wishes without seeking consent from the court was not necessary in a democratic society.

The complaint made by Charlie's parents to the ECHR was that GOSH, by preventing Charlie from receiving life-sustaining treatment, had violated their and Charlie's Article 2 right to life and that the consequence of the order of the court was to violate their and Charlie's Article 5 right by depriving him of his liberty.⁸⁰ Questions, which had not been raised in *Glass*, about the standing of parents to make a complaint on their child's behalf were left unresolved; the ECHR considered it sufficient to address the parents' complaints under Article 2 and 5. Further, his parents argued that the decisions of the court taken according to the best interests of the child amounted to a disproportionate interference with their Article 8 right to respect for private and family life as the court failed to consider whether there was a likelihood of significant harm to Charlie. And that, contrary to their Article 6 right, the Court of Appeal had concluded, without hearing any evidence, that their decision would cause their child significant harm.⁸¹ The ECHR found all arguments to be manifestly unfounded. Article 2 did not require access to experimental treatment to be regulated in any particular way and the UK had a regulatory framework in place which was derived from the relevant European Directives.⁸² The UK also had a regulatory framework for the withdrawal of life-

⁸⁰ *Supra* n.77, [55].

⁸¹ *Ibid.*, [56].

⁸² *Ibid.*, [86-87].

sustaining treatment compliant with Article 2, which took account of the wishes of the child as expressed through his Guardian and GOSH had properly applied to the court so any complaint under Article 2 in this respect was also manifestly unfounded.⁸³ The ECHR considered there to be a lack of specificity as to the complaint under Article 5 and held that, in so far as it concerned the lack of procedural safeguards, the complaint raised the same issues of the availability of a domestic legal framework and application to domestic courts as considered in relation to Article 2 and did not add anything.⁸⁴ Viewing the complaint under Article 6 as supplemental to the complaint under Article 8 the ECHR concluded that there had been an interference with private and family life but one that was in accordance with the law and pursued the legitimate aim of protecting the ‘health or morals’ and ‘rights and freedoms’ of Charlie. On the question whether the interference was necessary in a democratic society, framed in terms of the argument that the appropriate test was one of risk of significant harm rather than best interests, the ECHR noted the broad consensus within domestic and international law placing the best interests of the child as paramount. Whilst the facts of the case were exceptional and was a lack of ECHR guidance on the point, the Court noted that the domestic courts had concluded there was a risk to Charlie of significant harm.⁸⁵ The legal framework had not been shown to be disproportionate, rather it was ‘meticulous and thorough; ensured that all those concerned were represented throughout; heard extensive and high-quality expert evidence; accorded weight to all the arguments raised; and were reviewed at three levels of jurisdiction with clear and extensive reasoning giving relevant and sufficient support for their conclusions at all three levels’.⁸⁶ Respecting

⁸³ *Ibid.*, [85-98].

⁸⁴ *Ibid.*, [101-103].

⁸⁵ *Ibid.*, [118-199].

⁸⁶ *Ibid.*, [124].

the state's margin of appreciation, the existing principles and processes of English law were considered compatible with Convention Rights. That conclusion does not prevent English law from doing more to protect the rights of the child and of parents in dispute with professionals over the best interests of a seriously ill child. Whether English law could, or should, is not an issue to be settled in legal proceedings but requires independent and thorough review.

A Review of Children's Healthcare Law

The appeal process extended court proceedings over five months despite fast-tracked, time-pressured, hearings. The order made by Francis J was stayed five times, once pending the Court of Appeal hearing, once pending the application to the Supreme Court for permission to appeal and three times prior to the decision of the ECHR.⁸⁷ Whilst the appeal process was exhausted, the dispute between Charlie's parents and clinicians continued. Implementation of the order was delayed due to disagreements over Charlie's end of life care. In July 2017,⁸⁸ GOSH returned to the Family Division

⁸⁷ By the Supreme Court on the 8th, 9th and 19th June 2017 on the last occasion until midnight on the 10/11th July 2017, *Judgment of the UK Supreme Court in the Case of Charlie Gard*, 19 June 2017, <https://www.supremecourt.uk/news/latest-judgment-in-the-matter-of-charlie-gard.html>, [last accessed 4/8/17]; *European Court grants request for interim measure in Charlie Gard case until next Tuesday*, ECHR 189 (2017), [http://hudoc.echr.coe.int/eng-press#{\"itemid\":\[\"003-5741011-7295889\"\]}](http://hudoc.echr.coe.int/eng-press#{\), [last accessed 4/8/17]; The ECHR asked for the interim measures to be continued to enable a substantive application to be made, *European Court continues to grant request for an interim measure in Charlie Gard case*, ECHR 194 (2017), [http://hudoc.echr.coe.int/eng-press#{\"itemid\":\[\"003-5744700-7301406.\"\]}](http://hudoc.echr.coe.int/eng-press#{\) [last accessed 4/8/17]; And a further request to enable the court to consider the application once it had been received, *Substantive application has been lodged by Charlie Gard's parents; and interim measure is maintained pending proceedings on the case*, ECHR 203 (2017), [http://hudoc.echr.coe.int/eng-press#{\"itemid\":\[\"003-5755406-7315238\"\]}](http://hudoc.echr.coe.int/eng-press#{\) [last accessed 4/8/17].

⁸⁸ *Supra* n. 4.

so that Francis J could evaluate what Charlie's parents considered to be new evidence from the US doctor and other experts in the field. The judge gave the parents two days to secure written evidence so that he could determine whether it amounted to compelling new evidence which would enable him to revise his view. Mr Armstrong QC submitted that the evidence amounted to a respectable body of scientific opinion which supported the therapy. Proceedings before the Family Division took on a very different complexion as Francis J sought to facilitate resolution between GOSH and Charlie's parents, respecting the understandable concerns and distress of Charlie's parents and that of his doctors continuing mechanical ventilation which they viewed as harmful to him. A multidisciplinary meeting was held between the GOCH clinicians and Professor Hirano, chaired by an independent clinical ethicist and, as agreed during court proceedings the previous week, attended by Connie Yates. It was the MRI body scan performed at this time which persuaded Charlie's parents that his condition had deteriorated to such an extent that the proposed therapy would not work. Two further hearings were held over arrangements for Charlie's end of life care, during which Francis J pressed for mediation encouraging the parties to find a mutually acceptable solution. The relationship between the hospital and Charlie's parents irreparably damaged, they were unable to agree upon his end of life care. Upon the order of the court, Charlie was moved to a hospice, ventilation was withdrawn and Charlie died, one week before his first birthday.

As Francis J noted, the applicable legal principles are 'well settled'.⁸⁹ Established legal processes and principles have developed through the common law since the early 1980s

⁸⁹ *Supra* n. 16, [37].

without any opportunity for reflection upon the extent to which they place the child at the centre or help to repair the relationship

p or support parents and professionals to work together in the best interests of the child and without the opportunity for any reflection upon that practice in what is now a very different medical and social context. Francis J concluded his April judgment expressing the view that in such cases an Issues Resolution Hearing or mediation to determine the common ground could lead to greater understanding between the parents and the clinicians which may, in some cases, lead to a resolution.⁹⁰ Rather than the case revealing that the legal process could be improved by the introduction of an additional stage, I argue that the case reveals the need for a thorough review of the applicable legal principles and processes for responding to and resolving disputes between clinicians and parents about the medical treatment of a child. The case raises a host of questions which require careful reflection and considered deliberation, including:

What, if any, legal duties do/should healthcare professionals have to provide information about a child's medical condition and treatment in the context of a developing disagreement with parents over treatment?

What, if any, legal duties do/should healthcare professionals and/or Trusts have to respond to parental concerns about their child's medical treatment or to provide them with, or direct them to, reliable sources of support and advice?

⁹⁰ *Ibid.*, [130].

What are Trusts required to do to fulfil the obligation, as the ECtHR said in *Glass*, to ‘take the initiative and to defuse the situation’⁹¹ prior to making an application to court?

What, if any, role should clinical ethics committees have in such cases?

Should mediation be tried as a matter of course in such cases?

What support should be provided to parents to enable them to secure evidence which will enable the judge to determine the best interests of the child?

What should be the role of the Guardian, as court appointed representative of the independent interests of the child, in ensuring the judge is able to determine the best interests of the child?

Should legal aid be available to parents in such cases to ensure they are properly represented given the serious implications of the decision for their child’s life and their family life?

Are these cases most appropriately decided in the Family Division of the High Court?

Should a concern to resolve the dispute between clinicians and parents be balanced with the duty to reach an independent and objective determination of the welfare of the child?

⁹¹ *Glass v United Kingdom* (2004) 39 EHRR 15, [79].

Are the principles of law which have developed through the case law the most appropriate for resolving the issues and protecting the welfare of the child?

Should significant harm operate as a threshold in such cases as it does in/in a similar manner to public law proceedings under the Children Act 1989?

Are there differences depending upon whether the issue is the provision of pioneering, or experimental, or alternative, treatment or withholding, or withdrawing, treatment which need to be reflected in the legal principles or processes?

The decision of GOSH not to try nucleoside therapy was made on the grounds that it would not be ethical to maintain Charlie's life using a ventilator for the three months it would take to determine whether it was working. In the five months Charlie was on a ventilator whilst court proceedings were concluded he did not receive the treatment his parents were convinced would be beneficial. From the perspective of both his loving parents and the dedicated professionals caring for him this was not in Charlie's best interests. The process of trying to convince Charlie's parents of the futility of their hope was prolonged by the legal process as their hopes were raised by each appeal but then dashed as the view of the treating clinicians agreed by the judge continued to prevail. As Hazel McHaffie et al concluded from their study of parents of children whose intensive care was withdrawn, parents need to be 'personally persuaded that this course of action is the best for their child'.⁹² It was the MRI scan of Charlie's body in July

⁹² HE McHaffie, in association with PW Fowlie, R Hume, IA Laing, DJ Lloyd, AJ Lyon, *Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants*, (Abingdon: Radcliffe Medical Press, 2001), 397.

that persuaded his parents that the ‘window of opportunity has been lost for Charlie’ and that it was too late for the therapy to be effective. However, they remained convinced that had the therapy been administered when it was in prospect it would have improved his quality of life.⁹³ All parties, Charlie’s parents, clinicians, and the judges ultimately given the responsibility to decide, strove to secure what they genuinely considered the evidence to demonstrate was best for Charlie. The protracted legal process was traumatic for Charlie’s parents, stressful for Charlie’s clinicians and nurses and, Lady Hale said, put the judiciary in the position of being ‘complicit in directing a course of action which is contrary to Charlie’s best interests’.⁹⁴ Decisions were made by the judge about Charlie’s life-sustaining treatment, the experimental therapy and his end of life care but the legal process did not resolve the sincerely and strongly held differences of opinion between his parents and clinicians over what was best for him.

⁹³ Position Statement on Behalf of the Parents, Hearing 24 & 25 July 2017, [18], [32], <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> [last accessed 4/8/17].

⁹⁴ *Judgment of the UK Supreme Court in the Case of Charlie Gard*, 19 June 2017, <https://www.supremecourt.uk/news/latest-judgment-in-the-matter-of-charlie-gard.html>, [last accessed 4/8/17].